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Refugee children with communication disability in Rwanda: providing the educational services they need

Helen Barrett, Julie Marshall and Juliet Goldbart

Research undertaken in Rwanda aims to provide firm evidence for use in improving access to inclusive educational services for refugee children with communication disability.

The term ‘communication disability’ (CD) refers to the barriers to participation in society experienced by people who have difficulties understanding what others are trying to communicate to them or being understood when they try to communicate with others. Despite the inclusive nature of the early childhood development (ECD) and education policies of the Government of Rwanda (and of the humanitarian organisations providing support to these policies), implementation of ‘inclusive and equitable quality education’ (Sustainable Development Goal 4) for children who experience CD continues to be challenging, and many are excluded from the education system from an early age.

Education and ECD services for refugee children from the Democratic Republic of Congo and Burundi are well established in Rwanda. However, there are concerns about the level of access to these services for children who experience disabilities and for their families. Refugees who experience disabilities are recognised as being one of the most excluded and vulnerable groups of people in the world and are known to be under-identified. Consequently, the humanitarian support they need fails to reach them.¹ Those who **are** identified are likely to have visible or commonly recognised impairments. People with less visible challenges, such as intellectual or communication impairments, often go unnoticed, their exclusion perpetuated by a lack of identification and registration of their health, social, protection and education needs.

Communication disability includes diverse challenges which may exist independently or be part of other health conditions and/or impairments. CD is often perceived to be caused exclusively by hearing impairment and this understanding is

perpetuated by the use of the term ‘hearing and speech disability’ in the humanitarian sector. This ties the two impairments together under one disability label and serves to obscure the existence and needs of people with other types of communication disability, such as stammering or limited understanding of, or spoken, language, or those whose CD results from illnesses such as cerebral malaria, stroke or head injury who may be able to hear but who struggle to express themselves and/or understand others.

Addressing the evidence gaps

To address the lack of robust evidence around this topic, we are undertaking research in two Congolese camps and one Burundian camp in Rwanda, each at a different stage (post-emergency, protracted and emergency respectively) of humanitarian response.² This mixed method study also uses registration data from the UNHCR database on CD in Rwanda, analyses policies and guidelines pertaining to refugee registration, ECD and educational provision, and looks at qualitative data gathered from policymakers, service providers, community members and service users. The study aims, firstly, to understand the reasons why CD is under-identified. Secondly, it looks at the needs and wishes of carers of refugee children (aged 2–12) with CD, and the barriers the carers face in securing identification of needs and access to services for the children.

Analysis of UNHCR’s ProGres database undertaken in September 2017 revealed that only 0.01% of refugees in Rwanda are currently registered as experiencing a ‘speech disability/impairment’ and that only 10 out of almost 55,000 refugee children under 12 in Rwanda are registered as having a special educational need. Yet research suggests that

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15% of any population are likely to have a disability³ and prevalence may be even higher for refugees, some of whom may have trauma-related disabilities, including CD. It is clear from this initial analysis that prevalence of CD – and related needs – are currently under-estimated among refugees in Rwanda.

Initial analysis of interview and focus group data revealed that CD, as a concept, is misunderstood at all levels, from service users to policymakers. The UNHCR registration system for specific needs does not allow for registration of CD in forms other than ‘speech impairment/disability’ and ‘hearing impairment’. The interchangeable use of ‘impairment’ and ‘disability’ is the first point of confusion,⁴ the second being that CD often co-occurs with other impairments and/or health conditions. Most often, only one, or the most visible, impairment is documented but the associated disability and individual needs are not.

It is the responsibility of data collectors during initial registration/verification to decide if a person needs to be referred for a specific needs assessment – and a refugee’s needs may go unreported if the data collector does not communicate directly with them. This is particularly the case for highly stigmatised conditions, such as intellectual disability (that often leads to communication disability). Many children who experience CD are registered by an accompanying adult and their communication needs may not be reported or recorded. Data suggest that children with hearing impairment, particularly those who are non-verbal, are most likely to have their needs identified and registered. This may contribute to the misunderstanding that CD is solely related to hearing impairment and, as a result, may contribute to the focus on specialist services designed for the hearing-impaired (such as sign language tuition) to the exclusion of services addressing other needs.

As the needs of many children who experience CD are not even identified, it is unsurprising that their needs in an educational environment are largely unmet, with camp-based disability services in Rwanda focusing primarily on physical

rehabilitation and provision of assistive devices for physical and sensory impairments. Parents of children with disabilities are encouraged to send their children to the ECD centre or school but teachers feel unprepared to support them and education partners report having little knowledge and few skills within their organisations to train teachers on inclusive practices.

Some teachers have received some sign language training but the training has been sporadic and often without continuing support, leaving teachers trying to continue their sign language learning independently. When teachers leave, a skills gap remains. In addition, service providers at all levels tend to believe that sign language is a panacea for everyone with CD – a dangerous assumption since sign language is complex and should be taught consistently and with the inclusion of families, communities and service providers. It may also require considerable adaptation for people with limited understanding. Despite this, there is little evidence of knowledge or use of any methods of communication support other than sign language (such as picture- or symbol-based approaches which support understanding and may provide an alternative means of communication) to facilitate and support educational access.

Mainstream versus segregated learning

Despite mounting evidence that inclusive education is cost-effective and results in better educational and social outcomes for some children with disabilities and their peers, a number of children with mild/moderate intellectual impairment and associated CD, and children with hearing impairment, have been sent to residential special schools/centres outside the camps. This option is highly valued by parents as they – and teachers – believe this is the only way to give these children an education. However, the costs associated with sending children with CD away to segregated special education sites are high, and not only financially.

Parents and camp disability committees⁵ report a number of difficulties, including the isolation that children face when they return home in the school holidays as their families

continue to struggle to communicate with them and they have few, if any, friends outside their school environment. If anything, the children are reported to be more isolated after being sent to segregated residential schools/centres than before, and are considered to be 'different' by the community because they are no longer a part of it. Children with severe/profound CD, often associated with other impairments, are excluded both from specialist centres and their local mainstream school. Ironically, those with mild/moderate CD would be most able to cope in an inclusive mainstream ECD/school environment and the funding that is currently used to send a small number of these children to special schools could potentially be used to train and support entire teams of staff and many children in camp and host-community mainstream ECD centres and schools, and provide the additional resources required for children to access the curriculum.

Working together to identify solutions

Communities, service providers and carers of children with CD increasingly recognise the exclusionary nature of existing registration, ECD and education services, and desire services that better cater for their needs. Requests include:

- implementation of a community sensitisation programme to promote behaviour change
- training for carers and service providers on how to communicate with children using different methods
- training and skills development for teachers and education partners on inclusive education and inclusive teaching methodologies, plus ongoing support from experts in the fields of inclusive education and CD.

In order for services to respond to the needs of families supporting children who experience CD, it is critical that the families' voices are heard and that they are empowered to participate in service planning. We look forward to completing our study and formulating recommendations that

could improve access to inclusive ECD and education services for refugee children with CD in Rwanda, ensuring that no child is left behind.

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1. See FMR issue 35 (2010) on Disability and displacement www.fmreview.org/disability
2. The authors wish to thank UNHCR Rwanda (particularly Machtelt De Vries, Nathalie Busien, Anna-Katharina Reiser, Jackson Ndagijimana, Sophie Mwiseneza and Claudine Mukagatare), all implementing partners, and the refugees who took part in this research.
3. WHO and World Bank (2011) *World Report on Disability* www.who.int/disabilities/world_report/2011/report
4. Impairment is the actual condition, while a disability is the experience of functional limitation caused by the interaction between the condition, the social and physical environment, and the person.
5. Each camp has a disability committee with a representative from each quarter in the camp. The executive secretary of the disability committee sits on the camp executive committee.



FMR issue 35, July 2010 Disability and displacement

The 27 feature theme articles in this issue of FMR show why disabled people who are displaced need particular consideration and highlight some of the initiatives taken (locally and at the global level) to change thinking and practices so that their vulnerability is recognised, their voices heard – and responses made inclusive.

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